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### The behaviours that dementia care home staff in South Africa find challenging

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# The behaviours that dementia care home staff in South Africa find challenging: an exploratory study

## ABSTRACT

**Background:** Behavioural and psychological symptoms of dementia are often the reasons for moving to a care home. Care staff, often with limited dementia training, may have to support residents with distressed behaviour on a daily basis. Evidence about the support of residents with distressed or challenging behaviour in the South African context is lacking. This exploratory study aimed to gain an understanding of what care home staff perceived to be distressed behaviour, their coping strategies and how they learned to work with residents with behavioural symptoms of dementia.

**Methods:** An exploratory study was conducted among 17 participants working in four care homes in the Western Cape province of South Africa in 2014. Semi-structured interviews were audio-recorded. Data were analysed thematically.

**Findings:** Findings reflected the literature with regard to examples of behavioural symptoms of people with dementia that staff find challenging to manage. Overall, the majority of staff reported holding positive feelings about working with people with dementia. All preferred interpersonal approaches to manage distressed behaviour above medication although a small minority noted the use of medication in some cases. Dementia training was considered by most participants as an unmet need.

**Conclusion:** This exploratory study identified care home workers' desires for training about dementia and their preferences for interpersonal as opposed to pharmacological approaches to managing residents' distressed behaviour. The legacy of race and cultural perspectives in South Africa appears to still influence care practice and provision. Staff commitment, their interest in advancing their practice and their aspirations to offer more person-centred care were evident. Dementia training was identified as potentially helpful to care home staff who manage residents' distressed behaviour. Training should be developed in South Africa to promote good practice.

## **Introduction**

### **Background**

The increase in the prevalence of dementia as a result of the global ageing of the population is well documented (World Health Organisation (WHO), 2012). Long-term care facility residents often have a wide range of physical, social, behavioural, emotional and cognitive impairments. These present major challenges to staff. Family members may expect that their relatives with dementia will be cared for in facilities such as care homes by staff with experience and knowledge of dementia care.

The paucity of dementia related research in lower- and middle income countries has been highlighted (Prince et al., 2009). Some studies have been conducted in developing countries involving family or home-based care workers, such as that undertaken by the 10/66 Research Group (The 10/66 Dementia Research Group, 2004; Ridge, Makoni, Ridge, 2003; Makoni and Grainger 2002). However, the general lack of dementia research in residential facilities in South Africa means that we do not know whether experiences in other countries are similar or different. South Africa is unusual in its long-term care provision because while it is a developing country in many ways, it has a tradition of formal support for some older people (Seekings, 2002) including long-term care facilities for White older people (Department of Social Development (DSD), 2010). Residential care homes in South Africa are often referred to as offering care for the 'frail' (Older Persons Act (OPA), 2006). Following British Colonial traditions (Philpot, 2003), some frail or aged care homes have their origins in religious bodies' work but, more recently, commercial care developments such as retirement villages have emerged (see South African Care Forum, <http://sa-careforum.co.za>). Wide racial discrepancies in the availability of residential care for older people have characterised care homes in South Africa and their workforces, managers and trustees (DSD, 2010).

### **Distressed behaviour in care homes**

The high prevalence of distressed or challenging behaviour among care home residents is well documented internationally, as are its negative effects on care workers (Schmidt et al., 2012; Moniz-Cook et al., 2003; Corbett et al., 2013; Scott et al., 2011; Stokes, 2000; Ballard et al., 2001b). This behaviour often reduces quality of life for the resident, other residents and care staff (Buhr & White, 2006; Moniz-Cook et al., 2001; Schmidt et al., 2012). Schmidt et al. (2012) explored nurses' responses to distressed behaviour of residents with dementia in Germany. The nurse participants regarded aggressive behaviour as being the most distressing symptom to manage, followed by, in order of distress: depression/apathy; irritability/lability;

limited ability to communicate; hallucination/delusions; disinhibited behaviour; anxiety; aberrant motor behaviour and euphoria.

### **Coping strategies that staff employ to manage complex behaviour**

There is evidence that care staff in some countries regard interpersonal means of responding to aggressive behaviour as being the strategy of choice (Duxbury et al., 2013; Pulsford et al., 2011). This involves keeping calm, re-assuring the person, backing off rather than arguing back, and using de-escalation and distraction techniques. Interpersonal approaches include redirection, one-on-one care, validation, flexibility and using specific staff for care giving. Foley et al. (2003) commented on the benefit of family interaction with care staff in the successful management of distressed behaviour. Participants in their study reported that having background information about residents helped staff to identify behavioural intervention strategies for residents whose care posed particular challenges.

The overuse of controlling strategies of residents in care homes is a global concern. Over-medicating in aged care has resulted in calls upon governments to do more to protect residents' human rights in care homes (Frieden, 2010). Overuse of controlling strategies has also been a recent cause of concern in UK care settings (Banerjee, 2009; Ballard et al., 2001a; Stokes, 2000; James, 2011). Based on the evidence of the misuse of medication to manage distressed behaviour in people with dementia, the NICE/SCIE guidelines (2007) recommended that interpersonal means of responding to distressed behaviour should be used and use of controlling strategies, such as medication, isolation and physical restraint should be a last resort. The Mental Health Act (Act 17 of 2002) is currently the only legislation restricting the use of controlling strategies in people with dementia in South Africa. The guidelines for implementation of this Act make no mention of alternative approaches such as interpersonal or non-pharmacological approaches to dealing with distressed behaviour.

### **Aims/Objectives**

The primary aims of this study were to:

- Explore the possible unmet needs of staff working with residents with dementia in long-term care facilities (care homes) and what they might regard as effective support for themselves;

- Explore which behaviours of care home residents with dementia are regarded by care home staff as challenging to deal with and how they manage such behaviour;
- Hear from staff how they learn to deal with distressing or challenging behaviour.

## Methods

Qualitative interpretative studies are best suited for explorations of human behaviour and semi-structured interviews were the chosen method for this study (see Moriarty 2011). Based on a review of the literature, an interview schedule was developed to cover questions exploring experiences of working in care homes and questions and follow up probes asked participants their views of residents with dementia and any behaviours that are difficult to manage (see Box 1). It further explored ways that care workers' accounts of how they manage such behaviour and what forms it took. Demographic detail about the participants was also collected.

Insert Box 1 about here

Ethical approvals for this exploratory study were obtained from King's College London's Psychology, Nursing and Midwifery Research Ethics Sub-Committee (Ref PNM/13/14-15) and the Human Services Research Council (HSR 9/20/11/13) in South Africa. Managers of five care homes in the Western Cape, South Africa, were approached; four of whom agreed to participate in this study. The managers agreed that their staff could be approached for interviews and that the interviews could take place in the home during work time, providing that each would not exceed one hour in duration. As with the studies of Duxbury et al. (2013) and Papachristou et al. (2013), undertaken in similar settings in the UK, a sample size approaching 20 participants was regarded as sufficient to produce exploratory research findings of interest. Data were collected in February 2014 using semi-structured interviews which offered flexibility in exploring participants' contributions. The interviews (ranging between 25 and 57 minutes) were audio-recorded and transcribed for analysis. Computer assisted data management (ATLAS.ti) helped with the Framework Approach analysis (Spencer et al., 2014). Face to face interviews were preferred as these only required basic verbal and listening skills from participants which eliminated problems relating to literacy or writing. Care home workers directly working with residents with dementia were the focus of interest in this study not care home managers or supervisors. All participants' names homes have been anonymised.

#### Box 1: Summary of interview schedule

- What is your understanding of 'Dementia' / Alzheimer's disease?
- How long have you worked with people with dementia?
- How many persons with dementia have you cared for in the past?
- How do you feel about working with people with dementia?
- Can you describe a situation when a person with dementia displayed behaviour that was challenging to deal with?
- What does 'behaviour that challenges' in people with dementia mean to you?
- In your opinion, what is the cause for such behaviour? (triggers)
- How do you manage this behaviour?
- Describe how you feel when managing behaviour that challenges
- Where / how did you learn to manage this behaviour?

Participants were all day staff who did not rotate with night duty staff. Due to limited time and resources for this study, no members of staff working nights were approached for interview. Participants were either English or Afrikaans speaking and interviews were conducted in the participant's language of choice. Each participant was given an identifying number. Using Statistics South Africa (2014) descriptors, most participants were of 'Mixed race' of whom 14 were Afrikaans speaking; two were White and English speaking; and one was English Black African. The care home residents were predominantly white older people. To date, the majority of residents in care homes in South Africa are white although all ethnic groups have access to care homes. The workforce is determined by the ethnic group that dominates in each province and differ between provinces. The care homes participating in this study were from one province and which is not necessarily representative of all South Africa's care homes.

**Table 1: Participants' years of experience of care home work (n=17)**

<u>Years' experience in care home work:</u>	<b>NUMBER (years)</b>
6-10	
11-15	6
16-20	6
20+	2
	3

Specific care was taken not to collect details of participants' race/ethnicity demography as this could be construed as racist in post-apartheid South Africa.

## Key themes

Five main themes emerging from thematic analysis are reported below.

### *Attitudes toward working with people with dementia*

The majority of participants reported enjoying working with people with dementia although a small number described their work as a challenge, emotionally draining and very difficult. These two extracts illustrate the range of views:

'It is a pleasure, honestly. It is not difficult for me. It is sometimes exhausting, but I enjoy working with them.' (P13)

'It is difficult, but you have to handle it. Every day is like dealing with a different person, it feels like you are not getting anywhere. It is emotionally draining.' (P5)

Where staff had access to background information about residents they appeared to express more positive feelings about their work. In contrast, those who did not have access to such detail, perceived their work to be harder.

### *Distressed behaviour*

Examples of resident behaviours that were reported as distressing were most frequently related to aggression, non-compliance, difficulties in providing personal care, wandering and racism. This was evidenced by the number of mentions of each behaviour in the interviews (see Box 2). Examples included:

'They will attack you, be aggressive, grab you, pinch you and spit at you. It is not always easy.' (P18)

'Passiveness is a problem for me, it they just sit there and look at you expressionless.' (P10)

In the extract below, one participant reflected on racist behaviour of some residents that their dementia seemed to make it impossible to address:

‘They say bad things, racist things that they can’t take back, but you must pick yourself up and be patient.’ (P8)

Box 2: Interview content analysis by theme of difficulty mentioned

Resident Behaviour	Specific mentions
Aggression (including hitting, swearing, shouting, fighting, kicking, groping, attacking, blaming, falsely accusing, pinching)	17
Personal care (eg resisting eating, bathing, dressing and toileting)	13
Non-compliance (general apathy and non-cooperation)	11
Wandering (pacing and restlessness)	8
Racism	4

### *Management techniques*

The majority of management strategies adopted, according to the participants, reflected care-related or interpersonal approaches, such as talking ‘nicely’ and calming the resident, listening/paying attention to them, giving the resident ‘space’ and returning later when they were less distressed, going along with what they said or wanted, not opposing or contradicting them, and the use of non-verbal communication such as tone of voice, touch and eye contact:

‘Walk away and come back when they are calm. I talk nicely to them and use the information that I know about them such as ‘Ma’am, your sister is coming just now, we have to look nice when she comes’.’ (P13)

‘You need to earn their trust and respect, you think they don’t know, but they do. Communication plays a big role, verbal and non-verbal - talk, touch, smile, and give them attention. Make them feel special.’ (P16)

Others reported that involving residents in activities could reduce their distress: for example encouraging residents to help prepare vegetables (P2). Another (P13) reported playing music that individual residents particularly enjoyed and so making use of residents’ background information. Less frequently mentioned interpersonal approaches included offering treats, the use of ‘white lies’, or working with the less distressed residents before moving to others who were more challenging. Many care workers admitted



using 'white lies' (such as not correcting a resident or colluding with an error) to minimize resident distress. (The use of 'white lies' is sometimes controversial in countries such as the UK; James (2011) warns that it needs to be clarified when such lies are appropriate.)

A small number of participants mentioned the use of medication or physical restraint to manage distressed behaviour. Participants ~~in this study thought~~thought that doctors often prescribed too high doses of tranquilisers resulting in unresponsive residents who were difficult to work with. The use of medication and restraint was reportedly to be a last resort if interpersonal approaches were ineffective:

'Sometimes you have to restrain them until the medication calms them down.' (P6)

'Sometimes they are so overmedicated and are like 'zombies'. It is not nice if they are like that, because you cannot work with them if they are in that state.' (P5)

### *Training and education*

The majority of participants had basic school education and little or no dementia training. Less than half had attended a one day dementia workshop, but those with this experience reported that it had been informative and helpful in their work. Some spontaneously spoke about the benefit of training:

'I did a workshop, it wasn't too involved, only one day, but it really helped me. I am calmer and know better what to do. Before I had the training I would just pick up and go, but now I know you have to first tell the person what you are going to do, not just go ahead and do. Experience and internal training also helps a lot.' (P12)

Some participants valued experience over training, emphasising that they learned a great deal from working with people with dementia and from their colleagues. Participants also highlighted the value of internal (care home based) training and being supported by the 'sister in charge'. The majority of participants reporting positive feelings about working with people with dementia had basic level education (Grade 10). Those reporting mixed feelings about working with people with dementia had completed either Grade 11 or Grade 12 education and most of them had simply attended a one day dementia workshop. None of the contributors who had received internal training described feeling exhausted and emotionally drained by working with people with dementia. While there was possibly some association

between the level of education and how participants felt about working with people with dementia, the numbers are too small to perform any meaningful statistical analysis.

The average time that participants had been working with people with dementia was 15 years (see [Box Table 1](#)). Of the two participants reporting strong negative feelings working with people with dementia, one had 40 years' experience and the other 14 years. This suggests that, similar to level of education, length of experience did not necessarily influence how people perceived working with people with dementia but again numbers are too small to draw firm conclusions.

### *Managing distressed behaviour more effectively*

One aim of this study was to explore what care home staff thought might help them to manage residents' distressed behaviour more effectively. The most frequent suggestions related to acquiring knowledge (training) and access to residents' background information. About a third of participants considered that having more colleagues, time and skills would benefit them. Single references were made to the need for activities for residents, being consulted before people with dementia moved to the home, and having a smaller, but more consistent group of staff working with residents with dementia.

## **Discussion**

This exploratory qualitative study begins to unravel staff perspectives in an area of practice where staff attitudes to care may have a profound impact on residents. There are however several limitations to this study. Firstly the small number of care homes involved in this study means the findings may not be representative of all care homes in South Africa. In addition, there was little cultural or demographic diversity in the participants as most were Afrikaans speaking and were female. However, this profile was representative of care staff in the area where data were collected, based on the lead researcher's (AVW) experience of this area. A further limitation is that no night duty care workers were interviewed. This could have offered other valuable insights as some distressed behaviour typically presents at night, such as night time walking and confusion or disturbance in day-night cycle, and this would be an interesting area for research. Furthermore, participation was voluntary and so the findings may not include the perspectives of all care staff.

Nonetheless, this exploratory study is a first step to creating an evidence base of the experiences of care home staff in the South African context. The findings suggest that staff in care homes varied in their perceptions of working with people with dementia, but there were not many within-home differences. These aspects could be indicative of the leadership and culture in these homes, contributing to staff satisfaction and morale (Manthorpe, 2014). This is in line with the recommendations of the The Governance Institute (2009) which argues that good leadership is critical to healthcare organisations' success. No indicative association was found between level of education or years of experience and attitudes toward working with people with dementia. These results were similar to those reported by Schmidt et al. (2012) which indicated that the level of education did not result in stronger resilience amongst family carers of people with dementia.

Care staff mentioned aggression as the behaviour of people with dementia that they found most challenging to manage. This supports the findings of other studies conducted amongst staff caring for people with dementia in care homes internationally (Foley et al., 2003; Schmidt et al., 2012; Brodarty et al., 2003). The findings of this present study suggest that aggression from residents is distressing for care home staff in a South African context. The findings also indicate that apathy and /or non-compliance are difficult for care home workers since these were the second most distressing behaviour reported and so these too should be taken into account in training and supervision.

One notable behaviour that care home workers reported distressing to deal with concerned racist remarks made by residents with dementia. There is evidence from countries such as the UK that care workers from black and minority ethnic backgrounds are often subject to racism (Stevens et al., 2012). Specific care was taken not to enquire further about race during the interviews as this could be construed as racist in post-apartheid South Africa. The presence of a generation (or two generation) gap between care workers and residents may further exacerbate this problem. This may require training and skills development in the South African context to be particularly specific and evaluated in this context.

The majority of participants reported interpersonal approaches as their management strategy of choice. Approaches such as being calm and patient, talking 'nicely' and returning when the person with dementia was less distressed, all represent elements of a person-centred approach to care. Pulsford et al. (2011) and Duxbury et al. (2013) reported similar approaches to managing distressing behaviour in their studies of care homes.

The use of activities has been reported as an effective way of preventing boredom and thus reducing the prevalence of some distressed behaviours among people with dementia (Foley et al., 2003). As in the Foley et al. (2003) study, the use of activities and interpersonal approaches seemed to be associated with success in dealing with distressed behaviour. However, in none of the participating homes did the participants report any structured activities or therapeutic services for residents. Only a small number of participants commented on the physical environment as a possible trigger for distressed behaviour. It appeared that the process of care was regarded as a more important feature of successful behaviour management (Foley et al., 2003). Although a small number of participants reported using medication to manage distressed behaviour, the majority of participants reported a preference for care-related approaches as opposed to clinical approaches to managing distressed behaviour.

All participants commented on the potential value of having background information about residents particularly with dementia, but many reported no access to such information. Some care home managers were said to limit access to residents' personal files to the Sister in charge, this was indicative of other data in the interviews of a hierarchical 'divide' between care staff and management (including Sisters/nurses in charge).

There is growing international evidence that the proportion of staff receiving dementia related training is low, even among those working in specialist dementia services (WHO, 2012; Hussein and Manthorpe, 2012). This is surprising, considering the high prevalence of people with dementia or severe memory problems in care homes (80% in UK care homes) and the high percentage of these residents presenting with distressed behaviour. One theme that emerged strongly from the findings was that participants felt they would benefit from dementia related training. Less than a half reported having any dementia related training. Those who had received dementia training reported that it was limited to a one day workshop. Participants in this study echoed the views of participants in Beer et al.'s (2009) study who identified limited time (due to staff numbers) and lack of funds as barriers to attending training. The three most prominent training needs referred to by participants in this present study, explicitly or implicitly, were 1) managing distressed behaviour, 2) communication, and 3) aspects of person-centred care. Other possible interpretations of such data are that care workers might also benefit from supervision, working with a role model, or professional leadership.

As Nolan et al. (2008) stated there is often a lack of agreement between management and staff about staff training needs. Organisational needs may be prioritised over staff training. In its core principles for supporting people with dementia the WHO (2012) suggests that *“managers need to take responsibility to ensure members of their teams are trained and well supported to meet the needs of people with dementia.”*

Participants in this study indicated the need for more staff so that they could spend more time with residents with dementia, especially those with distressed behaviour. They reported that it takes longer to care for people with dementia as they need more time to understand and co-operate with care than other residents. As noted, the majority also considered that they had dementia related training needs while a small number expressed a need for greater acknowledgement from management of their hard work. Questions relating to staff numbers, training and acknowledgement may all be regarded as management responsibilities and may contribute positively to care staff feeling that they are supported by management which may lead to greater staff satisfaction (Manthorpe, 2014).

Person-centred care has been promoted widely in the literature for many years (Brooker, 2007; Kitwood, 1997) but none of the participants in this study reported coming across the term ‘person-centred care’. Nonetheless, without exception they described what might be considered to be person-centred approaches in their practice. This interpretation further supports the findings of Duxbury et al. (2013) and Pulsford et al. (2011) that dementia care staff regard interpersonal means of responding to distressed behaviour as the strategy of choice. There is a substantial body of evidence indicating that the principles of person-centred care amid functional analysis could be used to significantly improve distressing symptoms of dementia and reduce the burden on care staff (Moniz-Cook et al., 2003; Corbett et al., 2013; Duxbury et al., 2013). For trainers and managers this suggests ‘fertile ground’ for person-centred care practice if care staff find this approach to care potentially or intuitively attractive. It may be that there will be opportunities for staff to be informed of the principles of person-centred care and encouraged to use it in daily care as the subject of dementia is attracting growing interest in South Africa. While the evidence on the effectiveness of training is not robust (Moriarty et al., 2011) and has not been contextualised in South African care contexts, this present study suggests there may be promising approaches in building on existing communication skills. There may be scope for care home providers in South Africa in partnership with other stakeholders in the dementia care sector to specifically address communication skills to expand care workers’ knowledge, confidence and increase their understanding of how communication affects behaviour. Such initiatives would of course need to be evaluated.

## Conclusion

Despite the limitations of the study, the findings support those of other studies and add to the limited knowledge base with regard to care worker perspectives within a South African context. The behaviours that staff reported as distressing to deal with in residents with dementia reflect those in the literature. Strategies that staff employed to deal with distressing behaviour confirmed the preference for interpersonal approaches to care that are recorded in the evidence base. Although care staff seemed to find it difficult to identify possible causes for distressed behaviour, some seemed confident in managing this behaviour. There seemed to be consensus among care staff that dementia specific training would greatly benefit their practice and enhance their ability to provide care with confidence. The value of having access to background information about residents was clear to them all. Even in the absence of a national dementia strategy or similar in South Africa, some of the principles of person-centred care were evident in practice. Overall, most of those interviewed expressed a positive approach to caring for residents with dementia and expressed great empathy with residents, despite the distressed behaviour they frequently encountered. Future research may benefit from obtaining perspectives from multiple sources, including people with dementia, night staff, managers and supervisors, and family members, to better focus on the complex tasks of supporting residents with distressed behaviour.

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